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Translating the Science of Quality of Life into Practice: What Do Dermatology Life Quality Index Scores Mean?

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This study's aim was to determine the relationship between Dermatology Life Quality Index (DLQI) scores and a Global Question (GQ) concerning patients' views of the overall impairment of their skin-related quality of life (QoL), and to express this relationship by identifying bands of DLQI scores equivalent to each GQ descriptor. A DLQI questionnaire and the GQ were mailed to 3834 adult general dermatology outpatients. There were 1993 (52%) responses: male 841; female 1152. Mean DLQI score = 4.86 (range 0–30, standard deviation (SD) = 5.83). Mean GQ score = 1.22 (range 0–4, SD = 1.20). The mean, mode, and median of the GQ scores for each DLQI score were used to devise several sets of bands of DLQI scores, and κ coefficients of agreement calculated. The set proposed for adoption is: DLQI scores 0–1 = no effect on patient's life (GQ = 0, n = 754); DLQI scores 2–5 = small effect on patient's life (GQ = 1, n = 611); DLQI scores 6–10 = moderate effect on patient's life (GQ = 2, n = 327); DLQI scores 11–20 = very large effect on patient's life (GQ = 3, n = 242); DLQI scores 21–30 = extremely large effect on patient's life (GQ = 4, n = 59); κ coefficient 0.489. Banding of the DLQI will aid the clinical interpretation of an individual's DLQI score and allow DLQI scores to inform clinical decisions.

Key words: global question/quality of life/questionnaire/score meaning/skin disease
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Health-related quality of life (HRQoL) measurement assesses burden of illness and allows assessment of the outcomes of medical treatments (Calman, 1984; Price and Harding, 1993; Finlay, 1997). It can be defined as the subjective perception of the impact of health status, including disease and treatment, on physical, psychological, and social well-being. HRQoL in skin patients may be assessed using generic or specific HRQoL instruments (Bergner *et al*, 1981; Finlay and Kelly, 1987; Finlay and Khan, 1994). Validated dermatology-specific instruments include the Dermatology Life Quality Index (DLQI); Dermatology Quality of Life Scales; and Dermatology Specific Quality of Life and Skindex (Finlay and Khan, 1994; Chren *et al*, 1996; Anderson and Rajagopalan, 1997; Morgan *et al*, 1997). The DLQI is concise and user-friendly with only ten questions (Finlay and Khan, 1994) (see Fig 1). Its reliability and validity have been demonstrated (Zachariae *et al*, 2000; Hahn *et al*, 2001; Mork *et al*, 2002) and it has been used in over 137 studies in 20 countries (Lewis and Finlay, 2004).

Although high DLQI scores equate to high HRQoL impairment, interpretation of the clinical meaning of the scores is not adequately researched for the DLQI or for other dermatology HRQoL measurement techniques and this is a significant issue in dermatology (Schiffner *et al*, 2003). The lack of such information in dermatology is in contrast to other areas of medicine such as oncology (Osoba, 2002), spinal cord injury (May and Warren, 2001), and hematology (Gulbrandsen *et al*, 2004). Assessment of the "meaningfulness" of DLQI scores is essential if clinicians are to be able to use such measures as an aid to decision taking in patient management. It has been demonstrated that DLQI scores do change significantly if the clinical activity of psoriasis changes and that in psoriasis the DLQI can detect small but meaningful changes in clinical status over time (Mazzotti *et al*, 2003). This study uses an anchor question approach in order to establish ranges of scores reflecting patients' global rating of quality of life (QoL); this is considered an essential first step before addressing the question of minimal important difference.

It is believed that the examination of the relationship between DLQI scores and patients' view of their overall impairment of HRQoL will enhance dermatologists' understanding of the application of HRQoL outcomes in clinical practice.

Abbreviations: DLQI, Dermatology Life Quality Index; GQ, Global Question; HRQoL, Health-related quality of life; QoL, quality of life; SD, standard deviation; WL, waiting list

Declaration of interest: A.Y. Finlay is joint copyright owner of the DLQI; his department gains income from the use of the DLQI.

Results

From the 3834 patients who were posted the study pack, there were 1993 (52.0%) evaluable responses. Of these 1712 were on the waiting list (WL) and 281 had already been seen in outpatients (AS). The demographic details of those patients who had already been seen were very similar to those patients who were still on the WL. The only significant difference between these sub-groups was in the mean DLQI (WL = 4.70, AS = 5.79, $p = 0.0012$) and mean Global Question (GQ) (WL = 1.18, AS = 1.48, $p < 0.0005$) scores.

The aim of this questionnaire is to measure how much your skin problem has affected your life OVER THE LAST WEEK. Please tick one box for each question.

1. Over the last week, how **itchy, sore, painful** or **stinging** has your skin been?
2. Over the last week, how **embarrassed** or **self conscious** have you been because of your skin?
3. Over the last week, how much has your skin interfered with you going **shopping** or looking after your **home** or **garden**?
4. Over the last week, how much has your skin influenced the **clothes** you wear?
5. Over the last week, how much has your skin affected any **social** or **leisure** activities?
6. Over the last week, how much has your skin made it difficult for you to do any **sport**?
7. Over the last week, has your skin prevented you from **working** or **studying**?
   If "no", over the last week, how much has your skin been a problem at **work** or **studying**?
8. Over the last week, how much has your skin created problems with your **partner** or any of your **close friends** or **relatives**?
9. Over the last week, how much has your skin caused any **sexual difficulties**?
10. Over the last week, how much of a problem has the **treatment** for your skin been, for example by making your home messy, or by taking up time?

Please check you have answered every question. Thank you.

Each question is answered either "Very much" (score 3), "A lot" (score 2), "A little" (score 1) or "Not at all" (score 0). Questions 3 – 10 also have the option "Not relevant" (score 0). The first part of question 7 has the choices "Yes" (score 3), "No", or "Not relevant). The second part of question 7 has the choices "A lot", "A little" or "Not at all". The maximum score (indicating highest possible impairment of quality of life) is 30 and the minimum 0. Further information: www.ukdermatology.co.uk

Figure 1
The Dermatology Life Quality Index (Finlay and Khan, 1994).

The 1993 responders comprised 841 men and 1152 women, with a mean age of 57.5 y (age range 16–98 y, standard deviation (SD) 19.4). The non-responders comprised 706 men and 1135 women; therefore, 54.4% of the men sent a study pack responded whereas only 50.4% of the women responded. The ages of the non-responders were very similar to that of the responders (mean age of non-responders 50.3 y, SD 18.9).

The overall mean DLQI score was 4.86 (range 0–30, SD 5.83) and the mean GQ score was 1.22 (range 0–4, SD 1.20). The mean DLQI score for men (4.93, $SD = 5.74$) was similar to that for women (4.81 $SD = 5.88$), as was the mean GQ score (men 1.24, $SD = 1.15$; women 1.21, $SD = 1.25$). The Mann–Whitney *U* test also showed no significant difference between men and women for either the DLQI or GQ scores ($Pv = 0.266$ and $Pv = 0.143$, respectively). The Spearman rank correlation coefficient showed a strong correlation between the DLQI scores and the GQ scores ($r = 0.83$, $p < 0.01$).

For each score of the DLQI from 0 to 30, the number of patients with that score and their corresponding GQ score is shown in Table I. Figure 2 and Table I show the mode, mean, and median of the GQ scores for each DLQI score, and these were used as the basis for grouping the DLQI scores together into a set of five discrete bands, so that each band would correspond to a single GQ score. There are a few DLQI scores that could possibly be included in either of the two adjacent bands, such as DLQI scores of 11 and 12 could either be in the band corresponding to a GQ of 2, or in the GQ of 3 band. Similarly, DLQI scores of 21 and 22 could either be included in the GQ of 3 band, or in the GQ of 4 band. Separate sets of bands were therefore produced with different groupings of DLQI scores, and the κ coefficient of agreement calculated for each set of bands (Table II). These bands also emphasize the non-linear nature of the DLQI, a common characteristic of QoL measures. The κ coefficient is a measure of the level of agreement beyond that which could be expected by chance. The maximum level of agreement is a κ of 1.0, and values of 0.41–0.60 are considered a moderate strength of agreement (Altman, 1991).

The set of bands with the highest κ coefficient (0.493) was 0–1, 2–5, 6–12, 13–20, and 21–30. Another set of bands examined (0–1, 2–5, 6–10, 11–20, 21–30, Table III) had almost as high a κ coefficient, 0.489, and has in addition other merits that support this banding system being adopted for interpretation of DLQI scores in the general outpatient setting. The effect, and perhaps one of the advantages, of choosing this banding (Table III) compared with the banding with the highest κ score is to move 4% of the total study population from band 2 to band 3.

Subgroup analysis Considering the data (Table III) describing the proposed set of bands (0–1, 2–5, 6–10, 11–20, 21–30), there were a total of 59 patients whose actual GQ score was 2 or more points higher than the DLQI band would have predicted from their DLQI score. In contrast, there were only 18 patients whose actual GQ score was 2 or more points lower than predicted. All the patients whose GQ scores were 2 or more points away from the banding allocation were compared with those patients whose GQ scores agreed with the DLQI banding by carrying out a subscore analysis of the ten individual questions on the DLQI, and also by observing whether they had hand-written any comments on their questionnaire replies. There were five questionnaires (8.5%) out of the 59 patients with high GQ scores that had hand-written comments upon them. Two of these patients had written that they were very worried that their skin complaint might be cancer. These two patients had scored 0 and 1 on the DLQI, but had scored 4 and 2, respectively, on the GQ. There is no question on the DLQI that asks about patients' concerns regarding future health.

The sub-score comparison was carried out within each DLQI band (Appendix 1 online and Table SI). There was no single DLQI question that was consistently related to high GQ scores.

Dermatological conditions The 1108 referral letters analyzed for probable dermatological diagnosis revealed the following case distribution: 251 (22.7%) non-melanoma skin cancers and pre-malignant lesions; 234 (21.1%) benign skin and vascular tumors; 112 (10.1%) benign pigmented lesions and naevi; 108 (9.7%) eczematous conditions; 99 (8.9%) cases of acne and other disorders of sebaceous, apocrine and eccrine glands; 68 (6.1%) viral skin lesions; 60 (5.4%) psoriasis; 29 (2.6%) hair and scalp disorders; 20 keloid scars; 18 genital skin disorders; 18 pigmentary disorders; 17 urticarial disorders; 16 nail disorders; 15 superficial fungal infections; 12 pruritus; 11 reactive skin disorders and drug reactions; eight skin manifestations of possible endocrine disease; six purely bacterial infections; three scabies or lice infestations; two psychological skin disorders; and one immunobullous skin disease. Because of local referral practices, there were no patients with leg ulcers on the WL. Patients with suspected melanoma are not put on the WL.

Discussion

There has been great interest in the measurement of HRQoL in dermatology in recent years (Finlay, 2001). Although the reliability and validity of many disease-specific and dermatology-specific HRQoL instruments have been established

Table I. Numbers of patients with each DLQI score and details of the corresponding GQ score, with the mean, mode, and median of the GQ scores

	GQ score								
DLQI score	0	1	2	3	4	Mean (integer value)	Mode	Median	Patient totals
0	405	31	7		3	0.13 (0)	0	0	446
1	168	121	18		1	0.52 (1)	0	0	308
2	77	124	26			0.78 (1)	1	1	227
3	34	104	21	4		0.97 (1)	1	1	163
4	10	80	28	1		1.17 (1)	1	1	119
5	4	52	38	4	4	1.53 (2)	1	1	102
6		29	30	13		1.78 (2)	2	2	72
7	1	21	53	11	4	1.96 (2)	2	2	90
8		14	42	13		1.99 (2)	2	2	69
9		6	25	12	6	2.37 (2)	2	2	49
10	1	4	23	12	7	2.43 (2)	2	2	47
11	1	3	15	15	7	2.59 (3)	3	3	41
12		5	18	8	6	2.41 (2)	2	2	37
13	1		11	14	5	2.71 (3)	3	3	31
14		2	8	13	9	2.91 (3)	3	3	32
15			2	10	7	3.26 (3)	3	3	19
16		2		8	5	3.07 (3)	3	3	15
17			4	9	5	3.06 (3)	3	3	18
18			1	10	8	3.37 (3)	3	3	19
19			1	6	5	3.33 (3)	3	3	12
20				10	8	3.44 (3)	3	3	18
21			1	4	8	3.54 (4)	4	4	13
22			1	3	3	3.29 (3)	4	3	7
23				3	5	3.63 (4)	4	4	8
24				3	5	3.63 (4)	4	4	8
25				2	2	3.50 (4)	4	3.5	4
26				1	5	3.83 (4)	4	4	6
27					5	4.00 (4)	4	4	5
28				1	5	3.83 (4)	4	4	6
29					1	4.00 (4)	N/A	4	1
30					1	4.00 (4)	N/A	4	1
Patient totals	702	598	373	190	130				1993

DLQI, Dermatology Life Quality Index; GQ, Global Question.

through clinical studies, they are not yet accepted in clinical practice. Assessment of the meaning of scores of each instrument is the most important current challenge, beyond simply meeting the conventional psychometric requirements. Unfortunately, basic information about interpretation of the scores is not adequate either for the DLQI or for other HRQoL instruments and this area remains controversial (Testa, 2000). The concise format of the DLQI has facilitated this attempt at exploring HRQoL meaning in dermatology. Composite scores for QoL measures do suffer from inherent limitations and weaknesses; generalizability of scores should also be interpreted with caution, in particular when scores are related to individual patients. The purpose of this study, however, was to establish ranges by which to make overall scores more meaningful and thereby add to the information that can be gained by looking at the detailed sub-score profiles within the DLQI. It is not suggested that this approach dilutes the importance of

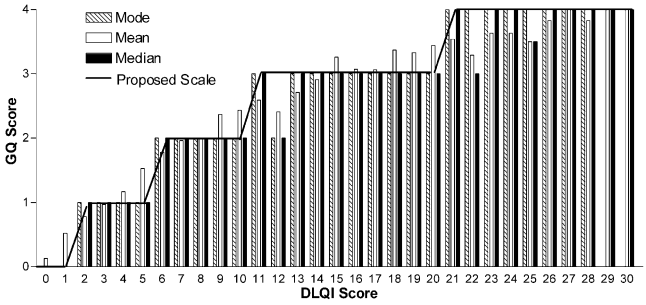

Figure 2
Relationship between the Dermatology Life Quality Index (DLQI) score and the mode, mean, and median of the Global Question (GQ) score. The proposed banding scale of DLQI scores 0–1, 2–5, 6–10, 11–20, 21–30 is also shown.

Table II. κ coefficients of agreement for separate possible sets of bands of the DLQI scores

Assignment of DLQI scores into bands					κ coefficient of agreement
Band 0	Band 1	Band 2	Band 3	Band 4	
0–1	2–5	6–12	13–20	21–30	0.493
0–1	2–5	6–12	13–22	23–30	0.490
0–1	2–5	6–10	11–20	21–30	0.489
0–1	2–5	6–10	11–22	23–30	0.486

DLQI, Dermatology Life Quality Index.

Table III. Proposed banding of the DLQI with the distribution of GQ scores for the bands 0–1, 2–5, 6–10, 11–20, 21–30; κ coefficient of agreement = 0.489

DLQI Bands (scores)	GQ score					Totals (%)
	0	1	2	3	4	
Band 0 (scores 0–1)	573	152	25	0	4	754 (38%)
Band 1 (scores 2–5)	125	360	113	9	4	611 (31%)
Band 2 (scores 6–10)	2	74	173	61	17	327 (16%)
Band 3 (scores 11–20)	2	12	60	103	65	242 (12%)
Band 4 (scores 21–30)	0	0	2	17	40	59 (3%)
Totals	702	598	373	190	130	1993

DLQI, Dermatology Life Quality Index; GQ, Global Question.

considering profile scores; however it is expected this information will complement the process.

Several different approaches to interpretation of HRQoL scores have been used, including population-based and anchor-based techniques. In this study, the anchor-based approach (Lydick and Epstein, 1993; Deyo and Patrick, 1995) was used as this is most appropriate for short, relatively simple questionnaires. This technique involves relating the domain scores to a GQ. Anchor-based methods have two requirements (Guyatt *et al*, 2002). First, the anchor must be interpretable: the GQ was clearly understood by participants. Second, there must be an appreciable association between the target and the anchor: this study demonstrated a very close correlation between the DLQI and the GQ. The use of the anchor technique in this study reflects previous work relating to HRQoL in childhood and adult asthma (Barber *et al*, 1996; Juniper *et al*, 1996a; Santanello *et al*, 1999) and rhinoconjunctivitis (Juniper *et al*, 1996b).

In this study, we have used the anchoring GQ as the basis for devising a "banded scale" of the total DLQI scores. The banding system that we propose for adoption is 0–1, 2–5, 6–10, 11–20, 21–30 ($\kappa = 0.489$). Although there was an alternative set of bands that had a minimally higher κ coefficient (0.493), which differed only in where the line was drawn between bands 2 and 3 (10–11 or 12–13), there are other factors to take into consideration. The proposed set puts DLQI scores of 11 and 12 into the higher band. DLQI scores of 11 were more often correlated with GQ scores of 3 and 4, than was the case for DLQI scores of 10 (this can be seen as a "step-up" in the graph in Fig 2). Furthermore, in order to score 11 points on the DLQI an individual has to score at least 2 ("a lot") on one of the 10 questions. Hence, on "common-sense" face value it seems more appropriate to group DLQI scores of 11, and therefore scores of 12, into the higher band. By having 11 and 12 in the higher band, the proposed banding scale gives much more easily remembered divisions, namely 0–1, 2–5, 6–10, 11–20, 21–30. It is also easy to remember that, once a DLQI score goes above 10, then this equates to the skin condition having a "very large effect" on skin-related QoL. Choosing a scale that is easy to remember has major implications for the acceptability and appropriateness of the DLQI's use in the routine clinical setting.

There may be several reasons why a few patients recorded a high GQ score but a low DLQI score. One reason may be that patients presenting with possible skin cancer may reflect their worry in a high GQ score, but the questions on the DLQI miss this factor.

The comparisons of overall responses between genders did not reveal any significant differences. It has been reported that males and females perceive their QoL to be affected differently (Harlow *et al*, 2000; Wijnhoven *et al*, 2003) but this was not the case in this study. If there had been significant differences, consideration would need to have been given to proposing different bandings for males and females.

Knowing the DLQI score in a patient may be helpful to inform the clinician when taking critical management decisions such as the initiation of systemic therapy in psoriasis, acne or atopic eczema, or decisions concerning admission for inpatient or intensive outpatient therapy. The DLQI score may also be useful to inform decisions about the clinical priority to be given to patients when resources are limited. This study indicates that if the DLQI score is greater than 10, the skin disease is having a very large effect on the patient's life. A DLQI score of greater than 10 would therefore generally be strong supportive evidence for the need for active patient intervention. In the outpatient population studied, 15% of patients had a score >10 (11% >12). If the DLQI is greater than 20 (only 3% of the population studied), this

indicates an extremely large effect on the patient's life and would generally indicate the need for very urgent, intensive intervention. The application of banding to the DLQI scores will allow harmonization, where appropriate, of treatment strategies between clinicians.

The proposed banding accords well with data from previous studies describing average baseline DLQI scores in cohorts of patients in whom active intervention was considered indicated. Examples in psoriasis include: the use of cyclosporin (median DLQI = 11.0, Touw *et al*, 2001); alefacept (mean DLQI = 11.3, Finlay *et al*, 2003); and admission for therapy (mean DLQI = 13.9, Kurwa and Finlay, 1995). Examples in acne include the use of oral isotretinoin (DLQI = 9.2, Newton *et al*, 1997). Examples in atopic eczema include the use of UVB (mean DLQI = 10.8, Piletta *et al*, 1996).

Although it is possible for a clinician to gain an overall view of a patient's QoL by asking a single question, the use of a more detailed questionnaire provides much richer detail that allows the clinician both to address specific problems experienced by a patient and to identify which aspects of the patient's life are most severely affected by their disease. Intervention can therefore be directed more appropriately.

It is believed that the findings of this study will help dermatologists to interpret DLQI scores and allow them to use this data in their clinical decision taking on a routine basis.

Materials and Methods

This was an open, prospective study of outpatients with general unselected skin diseases in a secondary-care setting. The DLQI, a dermatology-specific instrument, was chosen to assess the meaningfulness of scores against a single-item questionnaire (GQ) recording the patients' overall skin-related HRQoL. The study was registered as an audit project with the Cardiff and Vale National Health Service (NHS) Trust audit department and full ethical approval was obtained from the South East Wales Local Research Ethics Committee. This clinical investigation was conducted according to the Declaration of Helsinki principles. Approval was given by the R&D Department and the Data Protection Department of Cardiff and Vale NHS Trust. Permission was obtained from all the dermatology consultants in Cardiff for their patients to be involved in the study.

The majority of patients referred to UK hospital dermatology departments by general practitioners are placed on an outpatient WL. This is carried out after the referral letters are vetted by a dermatology consultant. Patients may have to wait several months before being seen by a dermatologist. In this study, patients were selected from the dermatology outpatient WL (n = 3569) or from patients seen in the clinic in the previous 2 mo (n = 523). From these 4092 outpatients, 3834 met the inclusion criteria of being aged 16 y and above and of having a skin condition, and they were posted a study pack containing a personalized invitation letter, a patient information sheet, questionnaires, and a freepost envelope. Two weeks after the first mailing, a follow-up pack was sent to the non-responders.

DLQI There are ten questions in the DLQI that ask the patient to define how his/her skin disease has affected his/her HRQoL over the last week (Fig 1). The sum of the scores provides a value between 0 (no involvement) and 30 (maximum impact on the HRQoL of the patient). The questions are easily understood, with an average completion time of 2 min (Loo *et al*, 2003), and fit onto a single side of A4 paper (30 × 21 cm). The DLQI measurement properties have been established over the last 10 y (Lewis and Finlay, 2004). Thus, the DLQI has the potential of becoming widely accepted as an aid to treatment decision taking in routine clinical practice. Although the DLQI has been partially psychometrically tested (Lewis and Finlay, 2004), some properties of this instrument have not yet been published.

GQ In order to examine the relationship between patients' assessment of their overall HRQoL and multi-dimensional DLQI scores, a GQ was used (Salek *et al*, 1992; Khan, 1993; Hyland & Sodergren, 1996).

"Over the last week, how much has your skin problem affected your life?"

The five possible response categories were:

Extremely large effect on my life (allocated 4 points)
Very large effect on my life (3 points)
Moderate effect on my life (2 points)
A small effect on my life (1 point)
No effect at all (0 points)

The patient had to tick one of five corresponding boxes.

Both the DLQI and GQ were printed on light colored paper to enhance response rate (Eiseman, 2000).

Dermatological conditions The patients were not asked for consent to look at their referral letters or medical records as this may have reduced the response rate. In order to describe the nature of skin conditions that typically appear on this department's outpatient WL, a separate selection of 1108 referral letters for different patients on the WL was made. These letters were analyzed by two of the authors (A. Y. F. and C. L. T.) to determine each patient's probable dermatological diagnosis. One "main diagnosis" was recorded per referral letter. (In the case of more than one skin problem per patient, the diagnosis that had triggered the referral was taken as the main dermatological diagnosis.)

Data processing and statistical analysis Data were entered and processed using SPSS version 11.0 for Windows (George and Mallery, 2002). A gender comparison was made using the Mann–Whitney *U* test. The Spearman rank correlation coefficient was used to examine the correlation between the DLQI scores and the GQ scores. The mean, mode, and median of the GQ scores for each DLQI score were used to devise separate sets of bands of the DLQI scores and the κ coefficient of agreement was calculated for each set.

Additionally, for those patients whose GQ score majorly disagreed (by two or more bands) with that predicted from the devised DLQI banding score, sub-score comparisons were made with those patients whose GQ scores agreed with the DLQI banding.

We wish to thank Sister M. Chawla for her help and the patients for contributing to the study.

Supplementary Material

The following material is available from http://www.blackwellpublishing.com/products/journals/suppmat/JID/JID23621/JID23621sm.htm
Appendix 1 online and Table S1. The frequency distribution of the sub-scores of each individual DLQ1 question.

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